



ACPA

American Cleft Palate
Craniofacial Association



Prenatal Diagnosis

acpacares.org

2026 Edition

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Foreword

Learning about a medical condition during pregnancy can come with a mix of emotions. Support is an important part of every family's cleft journey, and the American Cleft Palate Craniofacial Association (ACPA) is here to help.

- Better understand what a prenatal diagnosis is
- Make informed decisions during your pregnancy
- Prepare for the birth of your baby
- Find a cleft palate care team that's right for your family

The Process of Prenatal Diagnosis

Prenatal diagnoses are made during standard obstetric care to learn about the health and condition of an unborn baby. Your physician or hospital may use a variety of tools and methods to learn about your baby, including:

- Conducting blood tests
- Listening to the fetal heartbeat
- Conducting a physical examination
- Obtaining a sonogram by using ultrasound

Most obstetricians complete a detailed anatomic survey of the baby at some point between 18 and 22 weeks of pregnancy to do the following:

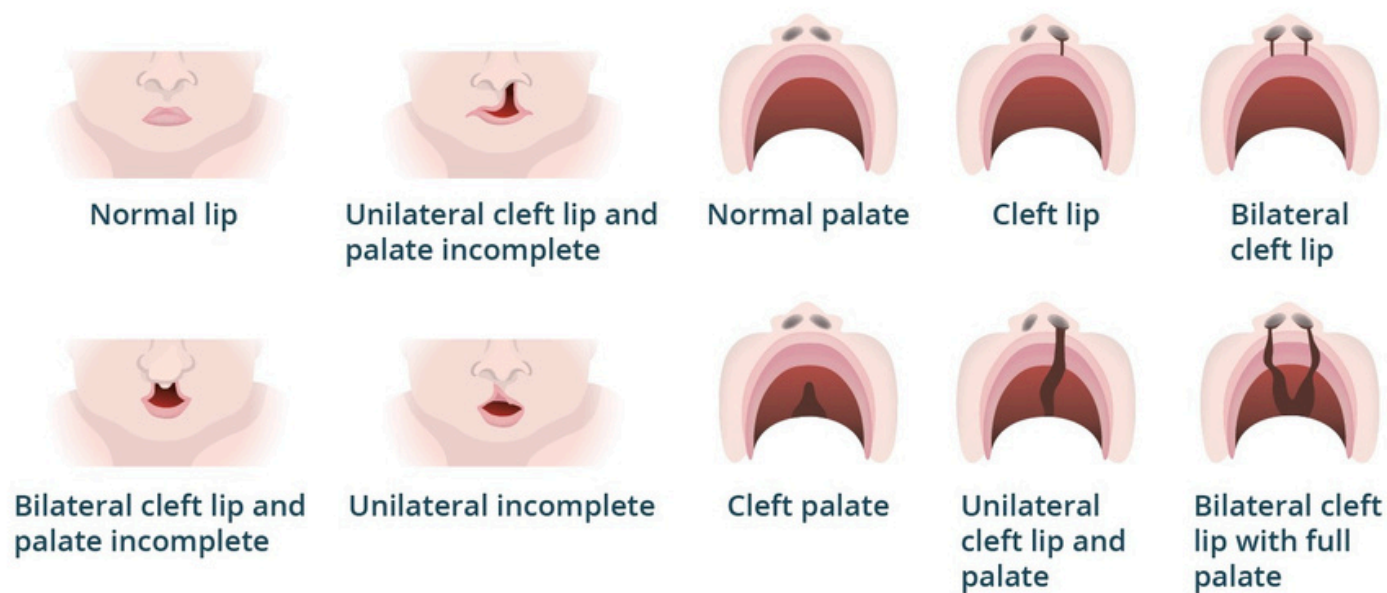
- Confirm pregnancy status
- Check on the growth and development of the fetus
- Learn the baby's sex
- Confirm the baby's due date
- Make sure the baby is healthy
- Identify conditions that may affect the baby before and after birth
- Help plan for labor, delivery, and post-delivery care if the baby has special health needs



Early prenatal diagnosis helps families and healthcare providers prepare for a baby's unique needs. Routine prenatal ultrasound often identifies cleft lip and/or cleft palate.

What Is a Cleft Lip? What Is a Cleft Palate?

A cleft is a gap in the lip and/or palate (the roof of the mouth). It may include the alveolar process (the bone) of the upper jaw and/or the upper gum. Clefts occur when the two sides of the lip or palate do not grow together during the baby's development very early in pregnancy.



Babies may be born with a cleft lip, a cleft palate, or both. A cleft lip usually occurs around the fifth week of pregnancy, before many women even know they are pregnant. A cleft palate usually develops around the ninth week of pregnancy.

Once a cleft develops, it remains throughout pregnancy and is present at birth. A cleft lip, with or without a cleft palate, will change the appearance of the baby's face. Most clefts can be closed through surgery, allowing a baby to eat and speak more easily. Many clefts can be repaired with little scarring.

HOW COMMON ARE CLEFTS?

In the United States, about 1 in every 1,600 babies is born with a cleft palate alone, and 1 in every 1,050 babies is born with a cleft lip with/without a cleft palate, making them among the most common birth differences. Left-sided clefts are more common than right-sided clefts. Some clefts are bilateral, affecting both sides of the mouth. About one-third of clefts involve the lip and alveolar ridge (the upper gum). Two-thirds of all clefts extend through the entire palate. Some clefts may involve the lip and soft palate but not the hard palate.



The National Birth Defects Prevention Study (1998-2004) reported that about 23% of babies born with a cleft had a prenatal diagnosis. **In 2019, that percentage rose to 65%.**

HOW WILL MY PHYSICIAN DETERMINE IF MY UNBORN BABY HAS A CLEFT?

Your physician may obtain an ultrasound (also called a sonogram) to determine if your unborn baby has a cleft. Ultrasonography uses sound waves to create a picture of a fetus. The pictures often appear in shades of gray. Darker gray areas are liquids, such as amniotic fluid. Lighter gray areas are solids, such as bones and teeth.

Most ultrasounds are two-dimensional, but your physician may use three-dimensional or four-dimensional ultrasounds, which show even greater detail. Your baby's size and position are ideal for ultrasonography between week 18 and week 26 of pregnancy.

In the best conditions, ultrasonography can produce pictures of cleft lip as early as the 20th week of pregnancy. Sometimes it can also help parents and physicians see clefts of the alveolar ridge. It is more difficult to get clear pictures of a baby's palate. Physicians miss more cleft palates with ultrasonography than they find. But as technology improves, identifying clefts of the palate will become more common. Larger hospitals and university medical centers are good resources for the most advanced ultrasound technology and prenatal diagnosis expertise.

WHAT CAUSES A CLEFT?

Clefts occur due to environmental or genetic factors that affect facial development. Clefts occur in all racial and ethnic groups. They occur slightly more often in people of Asian descent than in those of Caucasian descent, and least often in people of African descent.

FAMILY HISTORY OF CLEFTS

Your physician will ask about your family's general health history and specific questions about biological relatives who have clefts or other related birth differences. If your baby's mother, father, or grandparent had an isolated cleft lip and/or cleft palate, the baby may also have an isolated cleft (called a nonsyndromic cleft). If no one in the baby's family has had a cleft of the lip and/or palate (a negative family history), more information is needed to determine whether the cleft is isolated or part of a syndrome, which is the case in most pregnancies.

SYNDROMIC VERSUS NONSYNDROMIC CLEFTS

Most clefts of the lip and palate are isolated. If your physician finds additional birth differences beyond a cleft lip and/or palate, the cleft is called syndromic, meaning it is part of a syndrome. Your physician will need to gather more information to determine whether a cleft is syndromic or nonsyndromic.

ASSOCIATED DIFFERENCES

A syndrome is a group of signs or symptoms that often go together. Your physician may be able to explain how these symptoms affect your baby's growth and development. Often, the causes of birth differences are unknown. Your physician may suggest an additional consultation with a genetic specialist to gather more information.

GENETIC DIFFERENCES

If prenatal tests show more than one birth difference, your physician might suspect a genetic difference. Some babies with multiple birth differences have extra chromosomes (duplication), a

missing piece of a chromosome (deletion), or a rearranged chromosome. Children with genetic differences can have developmental delays. Isolated clefts are not usually associated with genetic differences.

Factors that increase the risk for a genetic difference include the following:

- The age of the pregnant person being 35 years or older
- Abnormal first-trimester or second-trimester screening results
- Presence of ultrasound soft markers, which are small differences that your physician may see during ultrasonography



Of all babies with cleft lip and palate, **10% to 15% are found to have a syndrome or genetic difference.** If tests show that chromosomes are normal, the risk of a syndrome drops to 8% to 10%.

SHOULD I HAVE ADDITIONAL PRENATAL TESTING?

Cleft lip and cleft palate can be repaired. Genetic differences cannot be repaired. The decision about additional testing for genetic disorders depends on how you might use the information you learn.

Some questions to consider might include the following:

- If additional prenatal testing shows that the baby may not survive long after birth or will have significant physical and/or developmental issues, will I continue the pregnancy?
- Will additional prenatal testing allow my family and me to prepare and educate ourselves about caring for a baby with special needs?
- If additional prenatal tests include those that carry a risk of miscarriage (an amniocentesis is one example), how do I balance the need for more information with the risk of miscarriage?

Your physician knows your specific situation and can provide information, guidance, and support as you make your decision. Genetic testing is available for families who find value in the additional information it may provide, but it is not necessary.

Sharing the News with Family and Friends

The more your family and friends know about clefts, the easier it will be for them to understand your journey and offer support. Your comfort with answering questions about clefts will set the tone for family, friends, and most importantly, your child. Brief responses may help others learn quickly about your baby's condition and give you more time to show off your beautiful new family member. For example, "My baby was born with a cleft. It will be closed when they are a little bigger." Practice until you find a response that feels right to you.

Focus on the positive in your explanation; your child hears and experiences your responses far more than they notice others' questions. Remember that a cleft is only one small feature of your child. Your child's cleft will not stop them from experiencing all the special things about childhood.

Planning Care for a Child with a Cleft Lip or Cleft Palate

The best care for a child with a cleft or other craniofacial birth difference happens when a family works with a cleft palate or craniofacial team. The team includes the child, the child's family, several physicians, and other cleft care specialists.

SELECTING A CLEFT CARE TEAM

Those who are born with cleft lip, cleft palate, and/or other craniofacial differences may require individualized treatment into adulthood. A team of specialists can best manage their care by working with the family to develop and follow a treatment plan. ACPA is dedicated to team care and to working for the best outcomes for patients.

You can find an ACPA Approved Team in your area by visiting www.ACPAcares.org or scanning this QR code.



MEMBERS OF THE CLEFT CARE TEAM

Team care begins at prenatal diagnosis for some, while for others it begins after birth. Your team will support you and your child throughout childhood, the teenage years, and beyond.

Cleft specialists who contribute to team care may include

- A surgeon (such as a plastic surgeon, an oral and maxillofacial surgeon, a craniofacial surgeon, or a neurosurgeon)
- A speech-language pathologist, who assesses speech and feeding problems
- A pediatric dentist, who works with children, or another dental specialist
- An orthodontist, who straightens the teeth and aligns the jaws
- A geneticist, who has training about human genes and screens patients for syndromes (see the Glossary of the ACPA publication "Your Baby's First Year"), including craniofacial (see the Glossary of "Your Baby's First Year") syndromes, and helps parents and adult patients understand the chances of having more babies with these conditions
- A nurse, who helps with feeding education and monitors the child's health
- A psychologist or other mental health professional who supports your child's and your family's emotional needs
- An audiologist, who assesses hearing
- An otolaryngologist, also called a head and neck surgeon or an ear, nose, and throat (ENT) specialist
- A pediatrician, a physician who specializes in monitoring your child's overall health and development
- Other specialists

QUESTIONS TO ASK WHEN SELECTING A CLEFT CARE TEAM

Your first visit with the cleft care team will include a consultation and an examination of your child. Then, the team will develop a comprehensive treatment plan for your child's short- and long-term care.

When you meet with the cleft care team, be prepared to ask questions and request additional information. Your questions may include these:

- Which specialists are on the team?
- What are the qualifications of the individual members of the team?
- What kind of experience does the team have?
- How do the team members communicate?
 - With each other?
 - With patients and families?
- Who will be the team contact person after our baby is born or after surgeries?
- Does the team prefer that parents use a particular type of modified cleft palate bottle over another?
- Who can assist with feeding if necessary at the birth hospital? During the first year of life?
- What is expected for the financial aspect of cleft care, and will my insurance cover it?



Treatment needs can change over time as growth and development occur. The focus of evaluation and treatment can include appearance, speech, hearing, ear health, dental development, overall health, and overall well-being.

Looking Ahead

As you prepare for your baby's birth, you have done one of the most important and positive things possible: you have begun educating yourself about prenatal diagnosis and its benefits for you and your family. At this moment, you may feel as if most of the attention is focused on the cleft rather than on the birth of your baby. We hope that as you continue to learn about caring for a child with a cleft, the cleft itself will feel like less of a focus. This will make room for plans and dreams for life with your baby and the child and person they will become.

If you are expecting a baby with a cleft, check out ACPA's additional resources for your journey by visiting www.ACPAcares.org/resource-center/





acpacares.org

FOR MORE INFORMATION

This booklet and many others have been produced by:

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